Implementing the Supplement

We designed the five lessons in this supplement to be taught in sequence for approximately 10 days, assuming class periods of about 50 minutes. The following pages offer general suggestions about using these materials in the classroom; you will find specific suggestions in the procedures of each lesson.

What Are the Goals of the Supplement?

Rare Diseases and Scientific Inquiry is designed to help students attain these major goals associated with scientific literacy:

- to understand a set of basic scientific principles related to the study of rare diseases and the relationships of rare diseases to common diseases and human health,
- to experience the process of scientific inquiry and develop an enhanced understanding of the nature and methods of science, and
- to recognize the role of science in society and the relationship between basic research and human health.

What Are the Science Concepts and How Are They Connected?

The lessons are organized into a conceptual framework that allows students to start with what they already know about disease and scientific inquiry, some of which may be incorrect. They then gain a scientific perspective on rare diseases and the importance of these diseases to medicine and to their lives.

Students begin by considering their initial thoughts about disease, its causes, what makes a disease rare, and what it might be like to cope with a rare disease (Lesson 1). Students then explore the three major causes of disease (genetics, environmental exposure, and infectious agents). They focus on the case of an infectious bacterium that can cause both a common and a rare disease (Lesson 2). We use a case study to explain how a rare disease is identified and to illustrate the sometimes difficult problem of obtaining an accurate diagnosis (Lesson 3). In Lesson 4, students investigate how medical research and clinical trials have affected the treatment of a rare disease.

Lesson 5, the final lesson, gives students an opportunity to consider what they have learned in the previous lessons. The creation of an informational poster has students reconsider what they learned about rare diseases: how the diseases are investigated, how medical research can affect their treatment, and what it is like to cope with one. The following chart (Table 3) illustrates the science content and conceptual flow of the classroom lessons and activities.

Table 3. Science Content and Conceptual Flow of the Lessons

Lesson	Learning Focus, from BSCS 5E Instructional Model	Major Concepts
Lesson 1—What Is a Rare Disease?	Engage	Students may have different ideas about the definition of "disease." They may also have naïve preconceptions about what makes a disease rare and how rare diseases are treated, and they may have attitudes about people with rare diseases.
Lesson 2—What Causes Rare Diseases?	Explore	Diseases have three main causes: genetics, environmental exposure, and infectious agents. These three influences sometimes interact with each other. An infectious agent may be able to cause a common disease in one case and a rare disease in another case. Doctors must ask testable questions and collect evidence to answer such questions when coming to a diagnosis.
Lesson 3—The Difficulty of Diagnosis	Explain	Some rare diseases are inherited. A rare disease may affect multiple body systems. Rare diseases sometimes share symptoms with more-common diseases, which can make getting a proper diagnosis difficult. People with a rare disease must sometimes cope with a stigma associated with being different from others.
Lesson 4—The Importance of Medical Research	Elaborate	A karyotype can provide evidence that a disease has a genetic cause. Some genetic diseases are inherited, while others are not. Much medical information is available online, but not all of it is useful or reliable. Clinical trials are an application of the scientific method to medicine. They have helped improve treatments for many rare diseases.
Lesson 5—Communicating about Rare Diseases	Evaluate	Patient support groups, government agencies, and other organizations exist to provide reliable information about rare diseases to the public. Knowledge about rare diseases and their impacts on people's lives may reduce the stigma sometimes associated with having a rare disease.

How Does the Supplement Correlate to the *National Science Education Standards*?

Rare Diseases and Scientific Inquiry supports teachers in their efforts to reform science education in the spirit of the National Research Council's 1996 *National Science Education Standards* (NSES). The content of the supplement is explicitly standards based. The following chart (Table 4) lists the specific content standards that this supplement addresses.

Table 4. Alignment of *Rare Diseases and Scientific Inquiry* Lessons with *National Science Education Standards* for Content, Grades 5–8

Table 4a. NSES *Standard A, Science as Inquiry*

As a result of activities in grades 5–8, all students should develop	Correlation to *Rare Diseases and Scientific Inquiry* Lessons
Abilities necessary to do scientific inquiry	1, 2, 3, 4
• Identify questions that can be answered through scientific investigations.	1, 2, 3, 4
• Design and conduct a scientific investigation. Students should develop general abilities, such as systematic observation, making accurate measurements, and identifying and controlling variables.	4
• Use appropriate tools and techniques to gather, analyze, and interpret data.	2, 3, 4
• Develop descriptions, explanations, predictions, and models using evidence. Students should base their explanations on what they observed, and as they develop cognitive skills, they should be able to differentiate explanation from description—providing causes for effects and establishing relationships based on evidence and logical argument.	1, 2, 3, 4
• Think critically and logically to make the relationships between evidence and explanations.	2, 3, 4
• Recognize and analyze alternative explanations and predictions.	2, 3, 4
• Communicate scientific procedures and explanations.	2, 3, 4
• Use mathematics in all aspects of scientific inquiry.	3, 4
Understandings about scientific inquiry	2, 3, 4, 5
• Different kinds of questions suggest different kinds of scientific investigations. Some investigations involve observing and describing objects, organisms, or events; some involve collecting specimens; some involve experiments; some involve seeking more information; some involve discovery of new objects and phenomena; and some involve making models.	2, 3, 4
• Mathematics is important in all aspects of scientific inquiry.	3, 4
• Scientific explanations emphasize evidence, have logically consistent arguments, and use scientific principles, models, and theories.	2, 3, 4, 5
• … Asking questions and querying other scientists' explanations is part of scientific inquiry.	2, 3, 4, 5

Table 4b.* NSES *Standards C, F, and G, Life Science, Science in Personal and Social Perspectives, and History and Nature of Science

As a result of activities in grades 5–8, all students should develop understanding of	Correlation to *Rare Diseases and Scientific Inquiry* Lessons
Standard C. Structure and Function in Living Systems	All
• … Different tissues are … grouped together to form larger functional units, called organs. Each type of cell, tissue, and organ has a distinct structure and set of functions that serve the organism as a whole.	2, 3, 4
• The human organism has systems for digestion, respiration, reproduction, circulation, excretion, movement, control, and coordination, and for protection from disease. These systems interact with each other.	2, 3, 4
• Disease is a breakdown in structures or functions of an organism.	All
Standard C. Reproduction and Heredity	2, 3, 4
• Every organism requires a set of instructions for specifying its traits. Heredity is the passage of these instructions from one generation to another.	2, 3, 4
• The characteristics of an organism can be described in terms of a combination of traits. Some are inherited, and others result from interactions with the environment.	3, 4
• Hereditary information is contained in genes, located in the **chromosomes** of each cell. Each gene carries a single unit of information. An inherited trait of an individual can be determined by one or by many genes, and a single gene can influence more than one trait. A human cell contains many thousands of different genes.	4
Standard F. Personal Health	1, 2, 4
• Natural environments may contain substances (for example, radon and lead) that are harmful to human beings.	1, 2, 4
Standard F. Risks and Benefits	1, 2, 3, 4
• Students should understand the risks associated with natural hazards (fires, floods, tornadoes, hurricanes, earthquakes, and volcanic eruptions), with chemical hazards (pollutants in air, water, soil, and food), biological hazards (pollen, viruses, bacterial, and parasites), social hazards (occupational safety and transportation), and personal hazards (smoking, dieting, and drinking).	1, 2, 4
• Individuals can use a systematic approach to thinking critically about risks and benefits.	3, 4
Standard G. Nature of Science	
• Scientists formulate and test their explanations of nature using observation, experiments, and theoretical and mathematical models.	2, 3, 4
• It is part of scientific inquiry to evaluate the results of scientific investigations, experiments, observations, theoretical models, and the explanations proposed by other scientists. Evaluation includes reviewing the experimental procedures, examining the evidence, identifying faulty reasoning, pointing out statements that go beyond the evidence, and suggesting alternative explanations for the same observations.	2, 3, 4, 5

Teaching Standards

The suggested teaching strategies in all the lessons support educators as they work to meet the teaching standards outlined in the *National Science Education Standards* (NRC, 1996). This supplement helps science teachers plan an inquiry-based program by providing short-term objectives for students. It also includes planning tools such as the Science Content and Conceptual Flow of the Lessons chart (Table 3) and a suggested timeline for teaching the supplement (page 18). Teachers can use the supplement to update their curriculum in response to their students' interest in this topic. The focus on active, collaborative, and inquiry-based learning helps teachers support the development of student understandings and nurture a community of science learners.

The structure of the lessons enables teachers to guide and facilitate learning. All the activities encourage and support student inquiry, promote discourse among students, and challenge students to accept and share responsibility for their learning. Using the BSCS 5E Instructional Model, combined with active, collaborative learning, allows teachers to respond effectively to the diversity of student backgrounds and learning styles. The supplement is fully annotated, with suggestions for how teachers can encourage and model the skills of scientific inquiry, as well as foster the curiosity, skepticism, and openness to new ideas and data that characterize the successful study of science.

Assessment Standards

Teachers can engage in ongoing assessment of their teaching and of student learning by using the assessment components embedded in each lesson. The assessment tasks are authentic; they are similar in form to tasks that students will engage in outside the classroom or that scientists do. Annotations guide teachers to these opportunities for assessment and provide answers to questions that can help teachers analyze students' feedback.

How Does the BSCS 5E Instructional Model Promote Active, Collaborative, Inquiry-Based Learning?

The lessons in this supplement use a research-based pedagogical approach called the BSCS 5E Instructional Model, or the BSCS 5Es. The BSCS 5Es are based on a **constructivist** theory of learning. A key premise of this theory is that students are active thinkers who build (or construct) their own understanding of concepts out of interactions with phenomena, the environment, and other individuals. A constructivist view of science learning recognizes that students need time to

- express their current thinking;
- interact with objects, organisms, substances, and equipment to develop a range of experiences on which to base their thinking;
- reflect on their thinking by writing and expressing themselves and comparing what they think with what others think; and
- make connections between their learning experiences and the real world.

The three key findings related to student learning identified in *How People Learn* (Bransford et al., 2000), a comprehensive review of research on learning, support the pedagogical strategies promoted by implementing the BSCS 5Es:

- Students enter class with a variety of preconceptions that may later significantly interfere with learning if those preconceptions are not engaged and addressed.
- To develop competence in a given subject, students must build a strong foundation of factual knowledge within the context of a coherent conceptual framework.
- Students benefit from a metacognitive approach to learning that emphasizes goal setting and self-monitoring.

The BSCS 5Es sequence the learning experiences so that students can construct their own understanding of a science concept over time. The model leads students through five phases of active learning that are easily described using five words that begin with the letter *E*: Engage, Explore, Explain, Elaborate, and Evaluate. Rather than just listening and reading, students are also analyzing and evaluating evidence, experiencing, and talking with their peers in ways that promote the development and understanding of key science concepts. These inquiry-based experiences include both direct experimentation and development of explanations through critical and logical thinking. Students often use technology to gather evidence, and mathematics to develop models or explanations.

The BSCS 5Es emphasize student-centered teaching practices. Students participate in their learning in ways that are different from those seen in a traditional classroom. The following charts exemplify what teachers do (Table 5) and what students do (Table 6) in the BSCS 5E Instructional Model.

The following paragraphs illustrate how we implemented the BSCS 5Es in *Rare Diseases and Scientific Inquiry*.

Engage

Students come to learning situations with prior knowledge. The Engage lesson gives you the chance to find out what students already know or think they know about the topic and concepts to be developed.

The Engage phase of this supplement (in Lesson 1) is designed to

- pique students' curiosity and generate interest;
- determine students' current understandings about disease, the scientific study of disease, and their attitudes toward disease;
- encourage students to compare their ideas with those of others; and
- give you a chance to hear or read students' current conceptions, which you can address in the later lessons.

Explore

In the Explore phase of the supplement (Lesson 2), students investigate a variety of medical problems and consider possible causes for each. Students interact with medical reports, assess which problems pose the biggest risks, and act accordingly. The lesson allows students to express their developing understanding of rare diseases and scientific inquiry through analyzing and comparing data, analyzing hypothetical situations, and answering questions.

Explain

The Explain phase provides opportunities for students to connect their previous experiences and begin to make conceptual sense of the main ideas of the supplement. It also allows you to introduce formal language, scientific terms, and content information that might make students' previous experiences easier to describe and explain.

In the Explain phase (Lesson 3), students investigate a case study dealing with **Marfan syndrome**. Students

- explain, in their own words, concepts and ideas about the causes of rare diseases;
- listen to and compare others' explanations of the results with their own;
- become involved in student-to-student discourse in which they explain their thinking to others and debate their ideas;
- record their ideas and current understandings; and
- revise their ideas.

Elaborate

In the Elaborate lesson (Lesson 4), students make conceptual connections between new and previous experiences. They draw on their knowledge about rare diseases and scientific inquiry to investigate how medical research can help doctors diagnose and improve treatments for a rare disease. In this lesson, students

- connect ideas and apply their understandings of rare diseases and scientific inquiry to the treatment of childhood **leukemia**,

Table 5. Understanding the BSCS 5E Instructional Model: What the Teacher Does

Phase	*Consistent* with the BSCS 5E Instructional Model	*Inconsistent* with the BSCS 5E Instructional Model
Engage	• Piques students' curiosity and generates interest • Determines students' current understanding (prior knowledge) of a concept or idea • Invites students to express what they think • Invites students to raise their own questions	• Introduces vocabulary • Explains concepts • Provides definitions and answers • Provides closure • Discourages students' ideas and questions
Explore	• Encourages student-to-student interaction • Observes and listens to the students as they interact • Asks probing questions to help students make sense of their experiences • Provides time for students to puzzle through problems	• Provides answers • Proceeds too rapidly for students to make sense of their experiences • Provides closure • Tells the students that they are wrong • Gives information and facts that solve the problem • Leads the students step-by-step to a solution
Explain	• Encourages students to use their common experiences and data from the Engage and Explore lessons to develop explanations • Asks questions that help students express understanding and explanations • Requests justification (evidence) for students' explanations • Provides time for students to compare their ideas with those of others and perhaps to revise their thinking • Introduces terminology and alternative explanations after students express their ideas	• Neglects to solicit students' explanations • Ignores data and information students gathered from previous lessons • Dismisses students' ideas • Accepts explanations that are not supported by evidence • Introduces unrelated concepts or skills
Elaborate	• Focuses students' attention on conceptual connections between new and former experiences • Encourages students to use what they have learned to explain a new event or idea • Reinforces students' use of scientific terms and descriptions previously introduced • Asks questions that help students draw reasonable conclusions from evidence and data	• Neglects to help students connect new and former experiences • Provides definitive answers • Tells students that they are wrong • Leads students step-by-step to a solution
Evaluate	• Observes and records as students demonstrate their understanding of concept(s) and performance of skills • Provides time for students to compare their ideas with those of others and perhaps to revise their thinking • Interviews students as a means of assessing their developing understanding • Encourages students to assess their own progress	• Tests vocabulary words, terms, and isolated facts • Introduces new ideas or concepts • Creates ambiguity • Promotes open-ended discussion unrelated to the concept or skill

Table 6. Understanding the BSCS 5E Instructional Model: What the Students Do

Phase	*Consistent* with the BSCS 5E Instructional Model	*Inconsistent* with the BSCS 5E Instructional Model
Engage	• Become interested in and curious about the concept/topic • Express current understanding of a concept or idea • Raise questions such as, What do I already know about this? What do I want to know about this? How could I find out?	• Ask for the "right" answer • Offer the "right" answer • Insist on answers or explanations • Seek closure
Explore	• Use materials and ideas • Conduct investigations in which they observe, describe, and record data • Try different ways to solve a problem or answer a question • Acquire a common set of experiences so they can compare results and ideas • Compare their ideas with those of others	• Let others do the thinking and exploring (passive involvement) • Work quietly with little or no interaction with others (only appropriate when exploring ideas or feelings) • Stop with one solution • Demand or seek closure
Explain	• Explain concepts and ideas in their own words • Base their explanations on evidence acquired during previous investigations • Record their ideas and current understanding • Reflect on and perhaps revise their ideas • Express their ideas using appropriate scientific language • Compare their ideas with what scientists know and understand	• Propose explanations from "thin air" with no relationship to previous experiences • Bring up irrelevant experiences and examples • Accept explanations without justification • Ignore or dismiss other plausible explanations • Propose explanations without evidence to support their ideas
Elaborate	• Make conceptual connections between new and former experiences • Use what they have learned to explain a new object, event, organism, or idea • Use scientific terms and descriptions • Draw reasonable conclusions from evidence and data • Communicate their understanding to others • Demonstrate what they understand about the concept(s) and how well they can implement a skill	• Ignore previous information or evidence • Draw conclusions from "thin air" • Use terminology inappropriately and without understanding
Evaluate	• Compare their current thinking with that of others and perhaps revise their ideas • Assess their own progress by comparing their current understanding with their prior knowledge • Ask new questions that take them deeper into a concept or topic area	• Disregard evidence or previously accepted explanations in drawing conclusions • Offer only yes-or-no answers or memorized definitions or explanations as answers • Fail to express satisfactory explanations in their own words • Introduce new, irrelevant topics

- use and understand scientific terms and descriptions accurately and in context,
- draw reasonable conclusions from evidence and data,
- add depth to their understandings of rare diseases and scientific inquiry, and
- communicate their understandings to others.

Evaluate

The Evaluate lesson is the final phase of the instructional model, but it only provides a "snapshot" of what the students understand and how far they have come. In reality, the assessment of students' conceptual understanding and ability to use skills begins with the Engage lesson and continues through each of the other phases. Combined with the students' written work and performance of tasks throughout the supplement, however, the Evaluate lesson can serve as a summative assessment of what students know and can do.

The Evaluate lesson (Lesson 5) gives students a chance to

- demonstrate their understandings of rare diseases and scientific inquiry,
- share their current thinking with others,
- assess their own progress by comparing their current understandings with their initial ideas, and
- ask questions that take them deeper into a concept.

What's the Evidence for the Effectiveness of the BSCS 5E Instructional Model?

Support from educational research studies for teaching science as inquiry is growing (for example, Geier et al., 2008; Hickey et al., 1999; Lynch et al., 2005; and Minner et al., 2009). A 2007 study, published in the *Journal of Research in Science Teaching* (Wilson et al., 2010), is particularly relevant to the *Rare Diseases and Scientific Inquiry* supplement.

In 2007, with funding from NIH, BSCS conducted a randomized, controlled trial to assess the effectiveness of the BSCS 5Es. The study used an adaptation of the NIH supplement *Sleep, Sleep Disorders, and Biological Rhythms*, developed by BSCS in 2003 (NIH and BSCS, 2003). Sixty high school students and one teacher participated. The students were randomly assigned to either the experimental or the control group. In the experimental group, the teacher used a version of the sleep supplement that was closely aligned with the theoretical underpinnings of the BSCS 5Es. For the control group, the teacher used a set of lessons based on the science content of the sleep supplement but aligned with the most commonplace instructional strategies found in U.S. science classrooms (as documented by Weiss et al., 2003). Both groups had the same master teacher.

Students taught with the BSCS 5Es and an inquiry-based approach demonstrated significantly higher achievement for a range of important learning goals, especially when the results were adjusted for variance in pretest scores. The results were also consistent across time (both immediately after instruction and four weeks later). Improvements in student learning were particularly strong for measures of student reasoning and argumentation. The following chart (Table 7) highlights some of the study's key findings. The results of the experiment strongly support the effectiveness of teaching with the BSCS 5Es.

Evidence also suggests that the BSCS 5Es are effective in changing students' attitudes on important issues. In a research study conducted during the field test for the NIH curriculum supplement *The Science of Mental Illness* (NIH and BSCS, 2005), BSCS partnered with researchers at the University of Chicago and the National Institute of Mental Health. The study investigated whether a short-term educational experience would change students' attitudes about mental illness. The results showed that after completing the curriculum supplement, students stigmatized mental illness less than they had beforehand. The decrease in stigmatizing attitudes was statistically significant (Corrigan et al., 2007; Watson et al., 2004).

Table 7. Differences in Performance of Students Receiving Inquiry-Based and Commonplace Instructional Approaches

Measure	Mean for Students Receiving Commonplace Teaching	Mean for Students Receiving Inquiry-Based Teaching	Effect Size
Total test score pretest (out of 74)	31.11	29.23	Not applicable
Total test score posttest	42.87	47.12	0.47
Reasoning pretest (fraction of responses at the highest level)	0.04	0.03	Not applicable
Reasoning posttest (fraction of responses at the highest level)	0.14	0.27	0.68
Score for articulating a claim (out of 3)	1.58	1.84	0.58
Score for using evidence in an explanation (out of 3)	1.67	2.01	0.74
Score for using reasoning in an explanation (out of 3)	1.57	1.89	0.59

Source: C.D. Wilson et al. 2010. The relative effects and equity of inquiry-based and commonplace science teaching on students' knowledge, reasoning, and argumentation. *Journal of Research in Science and Teaching, 47*(3), 276–301.

Note: Effect size is a convenient way of quantifying the amount of difference between two treatments. This study used the standardized mean difference (the difference in the means divided by the standard deviation, also known as Cohen's *d*). The posttest scores controlled for the variance in students' pretest scores. The reasoning posttest scores controlled for variance in students' reasoning pretest scores at the highest level.

How Does the Supplement Support Ongoing Assessment?

Teachers will use this supplement in a variety of ways and at different points in their curriculum. The most appropriate way to assess student learning occurs informally at various points within the five lessons, rather than just once, formally, at the end. We integrated assessment components within the lessons. These "embedded" assessment opportunities include one or more of the following strategies:

- performance-based activities, such as developing graphs or participating in a discussion of health effects or social policies;
- oral presentations to the class, such as reporting experimental results; and
- written assignments, such as answering questions or writing about demonstrations

These strategies allow you to assess a variety of aspects of the learning process, such as students' prior knowledge and current understandings, problem-solving and critical-thinking skills, level of understanding of new information, communication skills, and ability to synthesize ideas and apply understanding to a new situation.

How Can Controversial Topics Be Handled in the Classroom?

Teachers sometimes feel that the discussion of values is inappropriate in the science classroom or that it detracts from the learning of "real" science. The lessons in this supplement, however, are based on the conviction that much can be gained by involving students in analyzing issues of science, behavior, health, and society. Society expects all citizens to participate in the democratic process, and our educational system must give students opportunities to learn to deal with contentious issues with civility, objectivity, and fairness. Likewise, students need to learn that science intersects with life in many ways.

In this supplement, students discuss, interpret, and evaluate basic science and health issues, some in light of their values and ethics. As students encounter issues they feel strongly about, some discussions might become controversial. The degree of controversy will depend on many factors, such as how similar the students are with respect to socioeconomic status, perspectives, value systems, and religious preferences. In addition, the language and attitude of the teacher factor into the flow of ideas and the quality of exchange among the students.

The following guidelines may help you facilitate discussions that balance factual information with feelings:

- Remain neutral. Neutrality may be the single, most important characteristic of a successful discussion facilitator.
- Encourage students to discover as much information about the issue as possible.
- Keep the discussion relevant and moving forward by questioning or posing appropriate problems or hypothetical situations. Encourage everyone to contribute, but do not force reluctant students into the discussion.
- Emphasize that everyone must be open to hearing and considering diverse views.
- Use unbiased questioning to help students critically examine all views presented.
- Allow for the discussion of all feelings and opinions.
- Avoid seeking consensus on all issues. The multifaceted issues that students discuss result in the presentation of divergent views, and students should learn that this is acceptable.
- Acknowledge all contributions in the same evenhanded manner. If a student seems to be saying something for its shock value, see whether other students recognize the inappropriate comment, and then invite them to respond.
- Create a sense of freedom in the classroom. Remind students, however, that freedom implies the responsibility to exercise that freedom in ways that generate positive results for all.
- Insist on a nonhostile environment in the classroom. Remind students to respond to ideas instead of to the individuals presenting those ideas.
- Respect silence. Reflective discussions are often slow. If a teacher breaks the silence, students may allow the teacher to dominate the discussion.
- At the end of the discussion, ask students to summarize the points that they and their classmates have made. Respect students regardless of their opinions about any controversial issue.